

"Disability to Ability" Enjoyed by All!

On May 31, 2002, the Arkansas Spinal Cord Commission (ASCC), with the Spina Bifida Association of Arkansas, held its tenth conference at the C. A. Vines 4-H Center in Ferndale. ASCC hosted over 230 clients, family members, professionals, speakers, staff and vendors in the largest attended one-day conference to date.

Entitled *Disability to Ability*, the conference offered a variety of opportunities to learn about spinal cord disability related issues. Key-note speaker Randy Snow brought

the packed auditorium to its feet during the opening session. His dynamic speaking ability and charisma definitely left the audience wanting more. Other highlights included Dr. Edgar Garcia-Rill presenting the latest strategies in spinal cord injury research, Dr. Tom Smith's educating children under IDEA and 504 and Dr. Tom Kiser's session on management of spasticity in spinal cord injury (SCI).

Ample opportunities to meet with the exhibitors at the conference

were available. Exhibitor booths provided information on services ranging from personal care products, medical technology, new wheelchairs and van modifications.

A number of great door prizes were awarded this year. U.S. Med Mark of Little Rock donated two \$50 bills and winners, Bettie Lou Grinning and Verla Claghorn, were practically jumping with joy as they received their prizes. Fred McLain won a tub transfer bench donated by National Seating and

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Benny Beals Retires



ASCC Executive Director Cheryl Vines presents a plaque honoring his 25 years with the Commission to Case Manager Benny Beals at the conference.

After 25 years with ASCC, Case Manager Benny Beals retired on June 28, 2002. Since 1977, Benny served as Case Manager in the Fayetteville office. His motto: "You must have convictions and

standards by which you live your life," was reflected in his 25 years with the Commission.

As his coworkers and clients can testify, Benny is a "man of few words," but within those words are much depth, humor and wisdom. Always a good listener, Benny used this attribute in skillfully assessing his clients' needs. His best advice for his clients was, "Maximize what you have. Don't concentrate on your limitations — everyone has limitations."

His fellow staff members and those individuals he served will miss Benny's dedication and soft spoken manner, along with the ingenuity and resourcefulness he displayed in providing case management services. His ability to provide

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SPINAL COURIER

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With Thanks

Donations received this quarter:

In honor of Steve Burris
Gurdon High School Student Body
In memory of Richard Land
Jerry & Penny Lanning
Alice & Bob Levins
Buddy & Carolyn McAllester
Arnold & Anita Prueter
Kelly, Lois & Paul Wood
In memory of Henry Smith
Katherine Smith
In memory of Nonie Stacy
Lois Pfeiffer

ASCC accepts tax deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Clothing Name Labels

Dear Readers:

I've found a good source for iron-on clothing name labels that may be of use to you. We recently had to move my mother-in-law into a nursing home and one of the requirements was that all her clothing had to have her name on it. We tried various marker pens but found them messy and hard to use on some items of clothing.

A search of the Internet turned up ConnText Label Company that offers a wide variety of cotton iron-on name labels at reasonable prices. We pur-

chased 50 labels for \$7, including postage. They worked great. However, I would recommend ordering twice as many labels as you think you need; we quickly used them all.

ConnText can be reached at **www.conntext.com** or at P.O. Box 1024, Great Barrington, MA 01230, or FAX them at **1-888-766-2985**.

Besides residents in nursing homes, these labels would be great for kids at camp or school and travel.

Tom Farley, Editor

From the Director

One of my favorite times at the Commission is when we have our conferences. Whether it's a regional conference somewhere around the state or our statewide conference every other year in Little Rock, I always look forward to it! These are the times I learn the most about who it is that the Spinal Cord Commission serves and what those folks need and want. I get to hear first hand about people's concerns as well as their accomplishments. Over the years I've watched a lot of folks grow up, some grow old and we've lost more than a few. But I also get to meet moms of new babies and folks who are "new injuries" and I know that we are indeed serving an important purpose. It's also a great time to see colleagues and friends who are our partners in providing services and learn what's new!

Our conferences are a good place to learn about what's new — that's why most of you come! This year we heard about medical issues, dealing with systems and the latest in SCI repair and regeneration. We heard Randy Snow, a motivational speaker from Texas, who made us all laugh and challenged us each to push forward. If you missed his talk, his book, *Pushing Forward*, is in our Resource Library — it is worth the time to read. Thanks to all of you who attended *Disability to Ability* this year. Hope you got as much out of the day as I did!

I have a challenge for you too! At our conference, I visited with Ms. Frances Burnett. She asked me a question I didn't know the answer to, so I'm passing it on to all of you. Ms. Burnett isn't telling her age but she has lived with her spinal cord injury since February, 1947 — over 55 years! She asked me if she held the record for Arkansas. Is there anyone who lives in Arkansas and was injured before 1947? If so, please give me a call. Ms. Burnett and I want to know!

Have a great summer; try to stay cool!

Cheryl L. Vines

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"Disability to Ability"

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Mobility of Memphis and Erin O'Brien won a 40-piece tool set donated by WalMart of Jonesboro. The Commission expresses thanks to all of the businesses who made the drawings successful by donating door prizes.



Margaret Morris of Little Rock, AR is the proud door prize winner of a teacher.



Zanetter White and son Randrell, of Warren, AR savor the lunch provided at the conference!



Randy Alexander with Project-AWIN of Pine Bluff, AR talks about working and Social Security benefits.

If you didn't come to this year's conference, make your plans now to attend one of the Commission's miniconferences next year. Don't miss the knowledge you'll gain, as well as the fun you'll have!



Debbie Cummings, CTRS at St. Vincent Rehabilitation Hospital in Sherwood, AR, presents her doggy friends in the afternoon session, Recreation: An Interactive Experience.



Bettie Lou Grinning of Hot Springs, AR is the happy winner of a \$50 door prize.



Young Spencer Dudzik of Clinton, AR is caught enjoying himself at the conference – what a super grin!

Special Show 2002

The Arkansas Department of Education, Special Education Unit is sponsoring *Special Show 2002 — Linking for Success* on **August 6 and 7** at the Statehouse Convention Center in Little Rock. At the general session on Wednesday, August 7th, Tom Whittaker, the first person with significant physical disabilities to climb to the summit of Mount Everest, will speak on "Riding the Avalanche."

The conference will cover a wide range of topics of interest to parents, general classroom and special education teachers and supervisors, administrators, paraprofessionals and other professionals and support

personnel that work with students with disabilities. Topics will include autism, behavior disorders, ADHD, inclusion modifications, ESL, assessment, transition, curriculum, co-teaching and much, much more.

The cost of the conference is \$65 for both days and includes lunch on the first day of the conference and a buffet breakfast on the second morning. For more information, visit the Special Show link on the ADE website at http://arkedu.k12.ar.us/pdf/special_show.pdf or contact the Arkansas Department of Education, Special Education at **501-682-4222**.

Managing Your Bowel Program - Part Two

by Tom Kiser, M.D., ASCC Medical Director

In my last article I discussed the basics of a “good” bowel program. In this article I would like to address more aggressive options, and potential developments which may become available in the future. You may want to look into these options if you are having a lot of difficulty with your present bowel program, or if you need to do your bowel program another way simply to improve your quality of life.

In general, try to avoid chronic use of rectal enemas, because this can result in over stretching of the lower bowel and chronic dependence on enemas. However, there is a system that may be lower risk, because it uses a low pressure, pulsed lavage system to evacuate the lower colon of stool. This system is called the **Pulse Irrigated Evacuation (PIE)** system and is commercially available. I do not have a patient on this system, so I have no practical knowledge of its use. The PIE system has not been rigorously researched, so it must be approached with these limitations in mind.

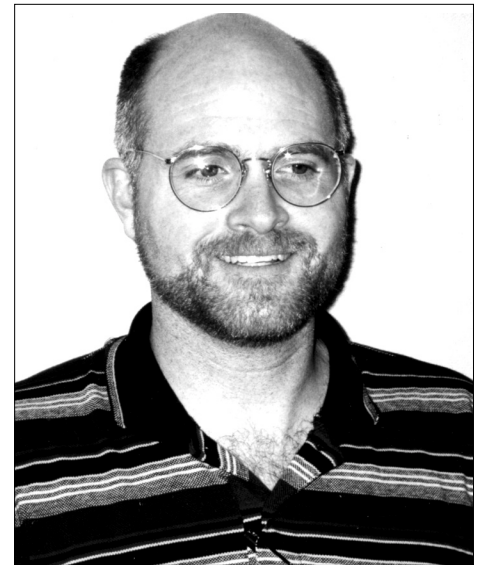
Low-pressure antegrade enemas via a surgical opening to the right colon are another option to consider. A catheter is implanted into the right (ascending) colon through the skin with X-ray guidance of a CT scan. At the Arkansas Children’s Hospital it is being used successfully in individuals with Spina Bifida. Another method is a permanent opening, created surgically. This method does not require placement of a catheter. The principle is the same, however: using either the catheter or the permanent opening, a low-pressure enema kit gently flushes the entire colon of all stool.

Sacral Root Nerve Stimulation with an implanted device was commercially available until last year,

when the company stopped selling it because it was unprofitable. By stimulating the sacral nerves to the lower colon and rectum, the evacuation of the lower bowel was greatly enhanced. At some point in the future this device may return to the market. A magnetic stimulation system, which can stimulate the sacral nerves to empty the lower bowel without requiring surgery, is currently being researched in animals. The magnetic device is placed over the skin near the sacral nerves. Time will tell whether this method proves as effective as the implanted device, and whether it will be affordable.

The final option I would like to discuss is a **colostomy**. The colon is surgically opened and sewn to the lower abdominal wall, and stool is collected in an external colostomy bag. If your bowel program is going well and you are not having problems, I do not recommend a colostomy. However, I have had several patients who have decided on a colostomy after we have discussed all the other options. One individual needed the help of a caretaker to perform his bowel program and had a job that required him to travel. This person elected to have a colostomy because he could manage it independently, and he has been happy with this choice. Another individual was unable to heal a pressure sore because he had to conduct his bowel program sitting on a bedside commode. After a surgical flap and a colostomy, the pressure sore is healed and he is quite satisfied with the outcome.

The important thing is to discuss the options and your current bowel program with your rehabilitation team (doctor, therapist and nurse), and talk with people you know who use the option you are interested in learning more about. Your



decision will be based on many factors and will ultimately be your choice.

Benny Beals Retires

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technical assistance to other agencies, families and community organizations in his role as ASCC Case Manager will unquestionably be missed in the northwestern area of Arkansas.

ASCC Executive Director Cheryl Vines presented Benny with a plaque for his 25 years of dedicated service to the Commission at the statewide spinal cord disabilities conference on May 31, 2002. Plans are being made to have a retirement luncheon in his honor later this summer.

Music has always been an important part of Benny’s life. As an accomplished guitarist, he has won many awards throughout the years. With his new found freedom of retirement, Benny plans to increase his guitar playing time. Who knows — we may see Benny’s name in lights at Branson in the future!

Whatever his future endeavors we know Benny will be successful and we wish him the best.

SAILS DeGray PlayDay X

August 24th

Mark your calendar now for the SAILS (Spa Area Independent Living Services) tenth annual DeGray PlayDay, Saturday, August 24th at the Caddo Bend Swimming Area of DeGray Lake near Arkadelphia. Activities start at 10:00 a.m. and usually wind down about 4:00 - 5:00 p.m. As always, a picnic lunch is provided at noon.

This is the tenth year for SAILS to host the one-day event providing people with disabilities from throughout the state the opportunity to come and try different types of recreational possibilities. Volunteers will be available to



assist you in doing whatever you wish to try — scuba diving, party barge, boat and jet ski rides, swimming, bingo or beach volleyball.

As always, the first registrants get an official DeGray PlayDay t-shirt. This year's color is tie-dyed, really appropriate for the tenth year . . . using all the previous colors for the last nine years!

Make your plans now to join SAILS Saturday, August 24th, 10:00 a.m. at DeGray Lake. For further information, call **501-624-7710** or toll free at **800-255-7549**.

Disney World Accessible Home Rentals

Will you be visiting Disney World this summer? If so, you may be interested in a new accessible vacation rental housing program located in Kissimmee, FL being offered by Medical Travel, Inc.

They have villas with three bedrooms/two baths in the Somerset Resort Community that are only four miles away from Walt Disney World. The units will also offer heated pools, sauna, jacuzzi, game room, tennis, billiards and exercise room at no extra charge.

For more information, visit their website at <http://www.medicaltravel.org> or call **800-778-7953**.



Arkansas Heat Can Be Deadly !

It's July in Arkansas and things are heatin' up! It's also time to remind

those with tetraplegia and high paraplegia that heat can be deadly. Persons with spinal cord injury (SCI) do not tolerate heat well because of the body's impaired ability to sweat. As a result, the body does not cool normally and body temperature rises to dangerous levels.

Symptoms of overheating for persons with SCI are vague but may include headache, rapid pulse, weakness and fatigue. If your temperature is high and you don't

suspect a fever, then cool down immediately!

Body temperatures over 100 degrees should be treated as a medical emergency. Remove the heat source (if possible) or move to a cooler environment. Cool the body as quickly as possible by removing clothes and applying wet towels or sheets. Seek emergency room (ER) care immediately and inform the ER personnel that overheating is suspected.

You can prevent overheating by:

- ☞ avoiding temperatures over 85°F, especially when the humidity is high
- ☞ wearing a hat

- ☞ staying out of the sun
- ☞ drinking lots of water to avoid dehydration
- ☞ wearing loose, light colored clothes
- ☞ keeping the skin damp with a spray bottle or wet towel
- ☞ using air conditioning or a fan to cool and circulate air
- ☞ minimizing your physical activity.

Summer heat can be deadly but can be prevented. Take steps now to keep your cool!

SCI Research — What's New?

Not too many years ago, SCI researchers were hard to find. These days, however, a wide variety of researchers are making



real gains into this complex problem. The following web addresses discuss the exciting research being conducted in the SCI field today.

Also, most of the sites have other useful links about SCI research.

www.apacure.com

The Christopher Reeve Paralysis Foundation. Check out the Research section and then look for the Areas of Research link for a basic overview of where research is being conducted.

www.spinalvictory.org

The Kent Waldrep Paralysis Foundation. A variety of different articles under The Research link.

www.electriciti.com/~spinal

The International Spinal Cord Regeneration Center in Tijuana Mexico. Dr. Fernando Ramirez del Rio offers embryonic cell transplant therapy.

www.miamiproject.miami.edu

The Miami Project to Cure Paralysis. A variety of information about SCI and research efforts for a cure.

www.proneuron.com/ MacrophageTherapy.html#

Proneuron Biotechnologies' research into macrophage therapy.

www.spinalcord.org/resource/ Factsheets/factsheet6.html

The National Spinal Cord Injury Association. Fact Sheet 6 discusses the importance of the scientific method in SCI research.

www.cbsnews.com/stories/2001/ 06/14/48hours/main296526.shtml

A CBS news story about the recent increase in funding for SCI research and the promising leads that researchers are pursuing.

http://depts.washington.edu/ rehab/sci/forum-research0501. shtml

The University of Washington School of Medicine talks about cell and gene therapy.

www.cnn.com/2000/health/12/ 11/spinal.cord.research.ap/ index.html

A story about Purdue University and the University of Indiana studying the effect of electrical current to stimulate nerve growth in damaged spinal cord cells.

www.miamiproject.miami.edu/ miami-project/Library/nl9904/ nl990467.htm

The Miami Project. An article discussing the scientific advances made in neuroscience in the last century and how those developments are being applied to SCI research.

Philadelphia Arts Guide

ARTREACH, Inc., had produced "Access the Arts, etc....A Guide for People with Disabilities." It is now available online at ARTREACH's Web site (**www.art-reach.org**), thanks to a generous grant from the Verizon Foundation.

The online version of the guide contains information on the physical and programmatic accessibility of cultural institutions for people with physical disabilities and those who are blind and deaf. More than 75 venues in Philadelphia and the

Accessible Art Web Site

Access Art, a collaboration between the Dayton Art Institute and Wright State University (WSU), makes art accessible to virtually everyone with a computer and an Internet connection — including people with visual, hearing and mobility impairments.

Using the latest accessibility standards and techniques, Access Art will provide alternative content in formats so people with adaptive equipment may easily navigate through the site. Since many people with mobility impairments do not use a mouse, the site's image-enlargement system lets them zoom in on an image by using a keyboard or similar device.

Access Art will allow visitors to select several tour options to explore the Art Institute's collection. Guided tours organize artwork according to selected themes, while custom tours are based on visitors' own personal interests or preferences. Check out the site at **www.daytonartinstitute.org/accessart**.

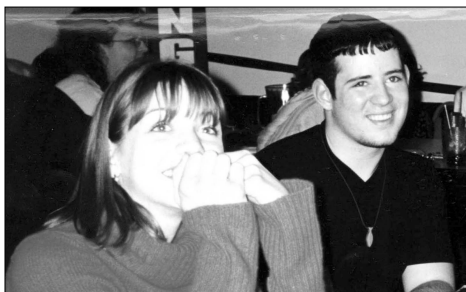
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greater Delaware Valley region are featured, providing the information necessary for educated choices about which cultural venues can accommodate special needs. Information is included about transportation, wheelchair accessibility, ticket acquisition, phone and TTD numbers and seating and special accommodations.

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Junior Rollin' Razorback Players are NWBA Academic All Americans



Arkansas Junior Rollin' Razorbacks members, Mary Allison Milford of Magnolia and Tyler Garner of Hot Springs, are two of the 2002 National Wheelchair Basketball Association Academic All Americans.

The National Wheelchair Basketball Association (NWBA) Youth Division named their Academic All American Team at the Youth Division Varsity National Championships in Birmingham, AL in March. Among the ten recipients were two Arkansas Junior Rollin'

Razorbacks, Mary Allison Milford of Magnolia and Tyler Garner of Hot Springs.

NWBA Academic All Americans must be high school students, hold a grade point average of 3.0 or better, submit three letters of recommendation and submit an essay. The All American Screening Committee is made up of NWBA Inter-collegiate coaches who select the ten recipients. This year there were over 35 applicants.

Mary Allison will be a Junior at Magnolia High School in the fall and Tyler will be a Junior at Lake Hamilton High School in Hot Springs. Congratulations to Mary Allison and Tyler and their proud parents, Deebe and Tom Milford and Becky and Doug Garner!

Three Rollin' Razorback Teams Place in the NWBA Top 5

The Arkansas Rollin' Razorbacks progressed to their 13th consecutive National Wheelchair Basketball Tournament (NWBT) March 29 - 30 in Champaign, IL. They won the East Regional and entered the NWBT as the #1 seed! Unfortunately, another national championship was not to be, as the Razorbacks were upset in the first round by the Phoenix Wheelchair Suns, 62 to 66. They ended the season ranked third.



The Junior Rollin' Razorbacks Varsity team qualified for the NWBA Youth Varsity National Tournament in Birmingham, AL March 15 - 17 for their fifth straight year. After wins over

Windy City (IL) Warriors and the Berkeley (CA) Cruisers, the Hogs ran into defending national champions Lakeshore (AL) Storm and suffered a close loss. Working back through the consolation bracket, they beat the Rancho (CA) Raiders to place 5th of 16 teams.

And finally, the youngest Rollin' Razorback team, the Ball Hawgs, qualified for the NWBA Youth Division Prep League Championships in Birmingham March 1 -2. In a field of 16 teams, the Ball Hawgs were our most successful Razorbacks this spring, with a great third place finish!

Congratulations to all of the Arkansas Rollin' Razorbacks for a great season!

2002 Spina Bifida Camp

Coach Cary Maddox, Golf Pro from First Tee of Arkansas (below), provides hints to first time golfer Brianna Collins of Camden at Spina Bifida Camp this year.



Forty-two kids with spinal cord disabilities from around the state attended Camp June 22 - 26 at Camp Aldersgate. The Arkansas Spinal Cord Commission partners with Camp Aldersgate and Med Camps of Arkansas to sponsor the Camp each year.

First Tee, a program created to provide accessible facilities to allow kids to learn golf, conducted clinics at Camp this year.

If you are interested in playing for the Rollin' Razorbacks, contact Coach Jared Johnson at rollinrazorback@cs.net or **501-834-8513**, or Junior Coach Doug Garner at dgarner728@aol.com or **501-525-4503**.

New Books Available in the Resource Center

The Source Book for the Disabled

You and your home, personal needs, the disabled parent and leisure and recreation are among the many contents of this source book. Full of illustrations and photographs, this is a comprehensive guide to easier and more independent living for physically disabled people, their families and friends.

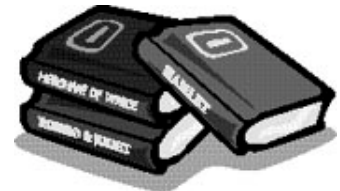
Accessible Gardening for People with Disabilities

Have you always wanted to get out of the house more and do something that shows your indi-

vidual style? Just check out this book on how to garden with ease from a wheelchair or walker. Whether you're a veteran gardener or it's your first time, this guide provides practical know-how necessary for designing, planting and maintaining a garden that suits your needs.

Living with Brain Injury, A Guide for Families

Helping people living with brain-injured survivors — both families and professionals alike — is what this book is all about. Keep up with the newest information



available including comprehensive facts on cutting edge neuroplasticity, experimental rehabilitation research and the process of rehabilitation itself.

Don't forget!

We have videos in the Resource Library that you can check out. From deer stand safety to catheterization and exercise, housing accessibility and sexuality — all are covered. Call **501-296-1792** or **800-459-1517** for more information about any of these resources today!

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